Newsletter July 2019
RAPID Special Edition

From the desk of RAPID Coordinating Principal Investigator

Palliative care continues to improve its evidence base for clinical prescribing. A complementary way of adding to the evidence base includes pharmacovigilance studies. Sometimes referred to as phase IV studies, post marketing data, or adverse drug reaction reporting, these studies are usually conducted retrospectively using clinical data of varying quality. The PaCCSC RAPID methodology uses active surveillance that prospectively collects, analyses and provides data on widespread and longer-term use of medications or non-pharmacological interventions captured from the time of prescribing using Case Report Forms.

RAPID uses minimal resources, is timely, involves clinicians from around the globe, and publishes each series to genuinely add to the knowledge for clinical prescribing and use of non-pharmacological therapies that are common place in palliative care practice. By defining the net benefit (clinical response together with harms) on data from the target audience, in this case palliative care practices around the world.

The evidence collected from these studies directly informs clinical practice, as well as, pharmaceutical policies around the world.

The RAPID Program has expanded significantly in the last 12 months with new series opening all the time and a number of prospective, consecutive cohort studies already completed. The Program has continued to develop over time and is now also offering studies in non-pharmacological interventions. The Program is also continuing to adapt this flexible methodology to look at its use in other quality improvement initiatives still using prospective, consecutive cohort studies. Excitingly, we are now moving into the Paediatric palliative and supportive care space with the first series opening later this month.

For each intervention evaluated by RAPID, data are collected prospectively from patients for whom the clinical decision has already been made by their treating clinician to prescribe the medication or use the intervention. No patient identifying data are collected. Key patient information includes only age and gender, and a computer generated identification number. No additional pathology tests are requested and only data from routine clinical care are used throughout each study.

At present, we have two more completed RAPID series for which papers are currently being drafted. We plan to publish the results of the aggregated data in the peer reviewed literature. The two series results currently being written up are ‘Oxycodone/Naloxone Desprescibing’ and ‘Hypodermoclysis’. Although sites who contribute data will be acknowledged in the publication, there will be no way of identifying individual patient’s or individual site’s data.

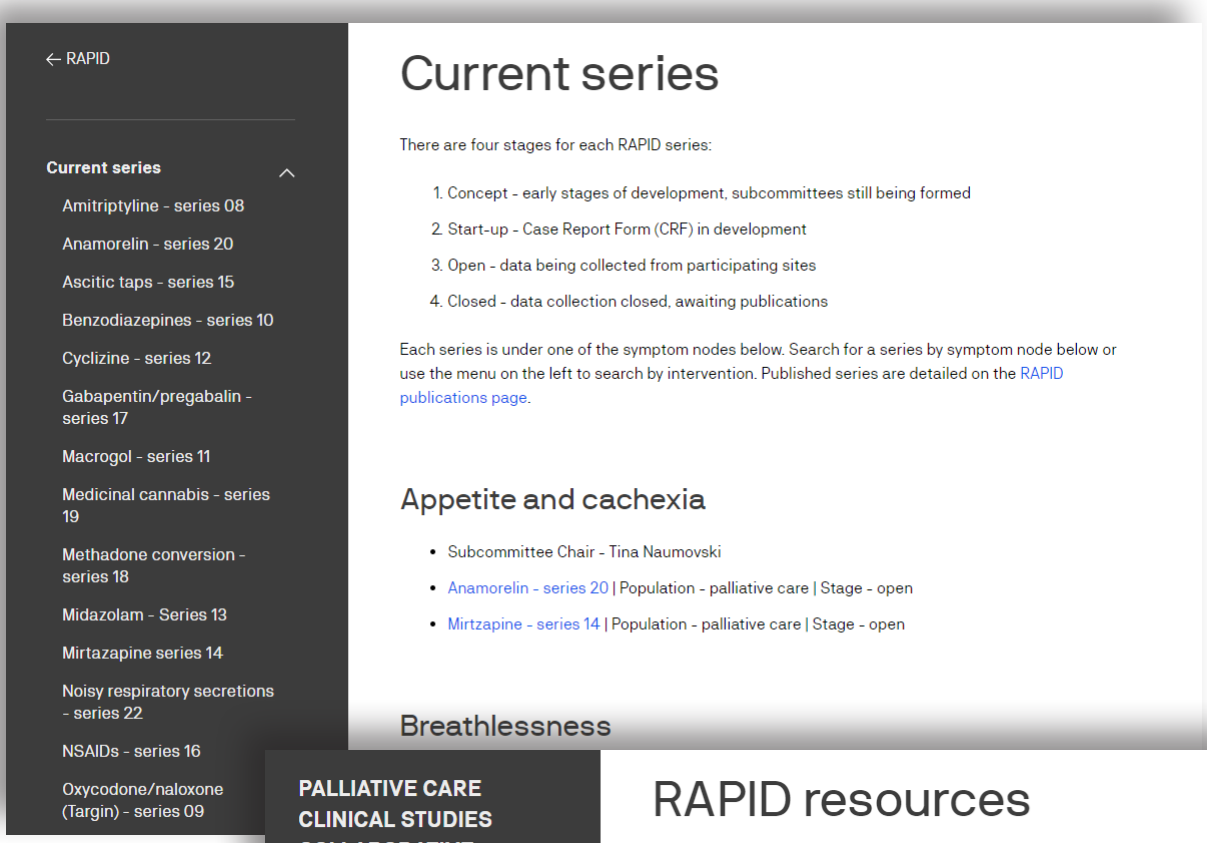
I invite you to become a PaCCSC member and join RAPID and participate in a truly global effort to improve clinical reporting and build the evidence base for clinical practice. I would also urge you to circulate this Special Edition Newsletter about the RAPID program throughout your networks to engage clinicians from far and wide. Please contact the RAPID Program team at RAPID@uts.edu.au for more information.

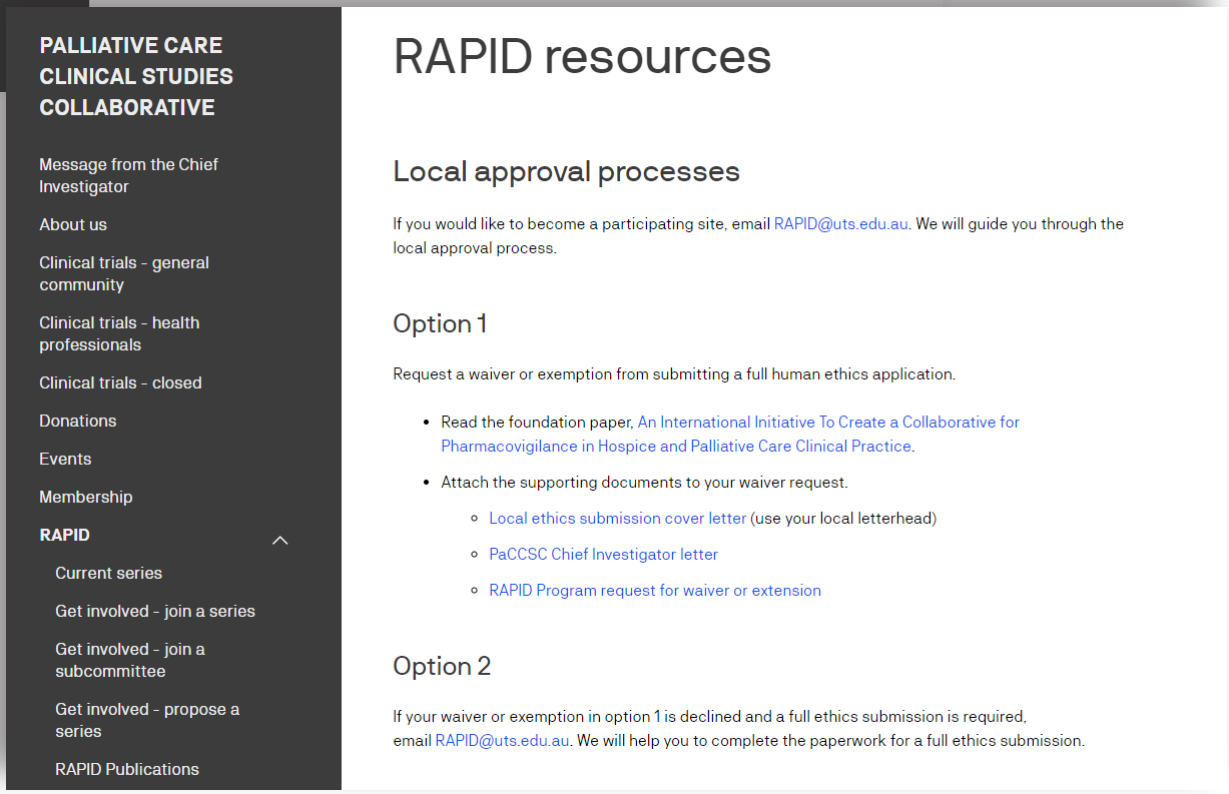
David Currow
RAPID Coordinating Principal Investigator

This Issue

Visit the RAPID Website!

The RAPID website is a fantastic resource that showcases all work currently underway, and all publications as a result of these series. Check the website for information about which medications and interventions are being investigated and how to get involved.





Go to uts.edu.au/RAPID

EXCITING NEW DEVELOPMENTS

RAPID Paediatric Program
First Paediatric Series - opening next month.
Gabapentinoids (gabapentin/pregabalin) - Series 23

What is this series about?

Gabapentinoids (gabapentin and pregabalin) are used for the management of neuropathic and nociplastic pain in paediatric palliative care (PPC) the two most significant groups felt to benefit clinically are children with cancer-related neuropathic pain and the significantly irritable child with severe neurological injury. It is common to use Gabapentinoids with other therapeutic agents in PPC which further complicates assessment of effect.

Clinical use of gabapentin or pregabalin is only supported by very low quality evidence even when the wider use of antiepileptic drug use in children's pain management is taken into account. However, a pointer to the potential 'real life' action of these medications comes from two pharmacovigilance studies in adult palliative care patients published in 2015.

The RAPID-Paediatric series seeks to establish the broad utility and toxicity of frequently used drugs in 'real life' paediatric palliative care situations across the world. It is designed to minimise the workload for any individual site through multi-site collaboration and enable RAPID data collection relatively quickly and easily.

In this study the data points are at baseline, day 14, day 28, 6 weeks and 12 weeks post baseline, as a reflection of the many conditions requiring a longer term involvement from PPC services and to ensure the opportunity for the majority of children to reach a therapeutic drug level. In this study we are hoping to establish the broad utility of gabapentin and pregabalin.

First Nursing Interventions Series - Open now
Noisy Respiratory Secretions - Series 22

What is this series about?

Noisy respiratory secretions are often observed in an imminently dying person. Despite the symptom occurring in up to 90% of patients, there is a lack of robust research to guide assessment or management. The cause of terminal respiratory secretions is unproven, but it is considered to be due to a pooling of respiratory secretions that occurs as a person becomes weaker, loses consciousness and the ability to cough or swallow. Family members and carers are often concerned that the noisy respiratory secretions may be distressing to the patient.

Your contributions to this series will improve our understanding on how effective repositioning a patient and/or suctioning are in the management of excess noisy respiratory secretions in the terminally ill palliative patient.

New Series - Open for data collection soon
Tranexamic Acid for Bleeding - Series 24

What is this series about?

When bleeding occurs, it is distressing for patients and their families, especially at the end of life. Bleeding can occur due to a number of underlying pathologies including haematological disorders, solid organ malignancies and other diseases / treatments resulting in disordered coagulation. Tranexamic acid is an anti-fibrinolytic agent which can be utilised in palliative medicine, haematology and other specialities to manage or prevent bleeding. The use of tranexamic acid is not clearly defined, particularly in the palliative medicine setting and concern regarding thrombosis continues to potentially limit its use in some settings where a symptomatic benefit may be obtained. This RAPID series aims to explore the use, efficacy, side effect and complication profile of tranexamic acid used in all patients for prophylaxis or treatment of bleeding.

New Series - Open now
Medicinal Cannabis - Series 19

What is this series about?

There is wide public interest in the role of medicinal cannabis in cancer care generally, and palliative care in particular. Despite this substantial interest, many clinicians in palliative care remain wary of prescribing medicinal cannabis. They cite concerns about the lack of evidence underpinning the role of medicinal cannabis, concerns about the potential for adverse effect and the unconventional way by which cannabis came to be listed as a medicine in many jurisdictions including Australia.

This RAPID series of Medicinal Cannabis in Palliative Care will address some of these concerns by establishing a significant database of real-time monitoring of patients prescribed cannabis who are receiving palliative care. These data will capture the benefits or effects, as well as adverse effects seen for patients. Specifically, all patients attending palliative care services who are prescribed medicinal cannabis for any indication will have a series of outcomes documented (1) at time of prescription, and (2) at subsequent standardised follow up times. Outcomes of interest include evidence of effects upon symptoms such as pain, appetite, nausea, sleep and upon overall quality of life. In addition, data will be collected around any evidence of adverse effects such as sedation, confusion and other potential side effects. The doses of cannabis and of other medications prescribed for symptom relief will be collected.

This important study will enable prospective monitoring of a medication that is already available and where the evidence underpinning its use is limited. Australian palliative care services are uniquely placed to contribute to this real-time data monitoring and reporting project with potential to inform practice worldwide.

New Series - Open for data collection soon

Opioids for Symptomatic Breathlessness - Series 21

What is this series about?

Breathlessness can be a frightening and overwhelming problem that is difficult to treat. For many people, breathlessness remains when all the underlying causes of breathlessness have been optimally managed (chronic breathlessness). Breathlessness in these circumstances often occurs at rest or doing routine things like showering or preparing meals.

The prevalence of chronic breathlessness will continue to increase as the population ages because the chronic progressive diseases where breathlessness is common are increasing in prevalence. Nearly one half of all people experience distressing breathlessness during the last year of life.

This series is different to other RAPID series (other than Anamorelin). In this series we want longitudinal data, at least for the sub-group who are on sustained release morphine (Kapanol) compared to other opioids and opioid formulations. The timepoints are open ended, and the next planned (or unplanned contact if that supervenes) is the point at which we want data, rather than setting those times beforehand.

Adopting this to the undertakings to the Therapeutic Goods Administration, we would want to continue data collection ad infinitum for Kapanol (beyond the first 100). Given that we are accepting all patients with symptomatic breathlesness, even 100 complete data sets to a T2 timepoint may not be sufficient, depending on how many different opioids and formulations are required.

SAVE THE DATE

PaCCSC 11th Annual Research Forum

Aerial Function Centre
UTS, Ultimo NSW

Become a member to receive updates about the Forum.

Thursday
12 March
2020

WE NEED YOUR HELP

AMITRIPTYLINE- Final Push

We are on a mission to complete the Amitriptyline series before the end of the year. ***We only need 26*** more completed data sets and we'll be finished. Can you help by collecting data for just one patient - if every site does this we will reach the 100 target and be able to close the series and begin analysing the data which would be fantastic!

Many thanks to those sites who have contributed data to this Series already!

Site	Count T_0	Count T_1	Count T_2
Sunshine Coast Hospital & Health Service QLD	4	4	4
Braeside Hospital NSW	4	3	0
Calvary Health Care Kogarah NSW	8	7	6
St Vincent's Hospital (Melbourne) VIC	0	0	0
Mercy Hospice Auckland NZ	4	4	3
Southern Adelaide Palliative Services SA	2	2	1
Wolper Jewish Private Hospital	1	1	1
St Catherine's Hospice Scarborough	4	4	2
Novia Scotial Health Authority	9	7	6
Care Plus Group	7	6	5
Arohanui Hospice	15	14	10
City Health Care Partnership CIC	2	1	1
Pecs University Medical School	4	3	2
St Leonards Hospice	1	1	1
Concord Hospital - Consult Service	2	1	1
Concord Centre for Palliative Care	2	2	1
Cranford Hospice	4	3	2
Liverpool Hospital	1	1	0
Te Omanga Hospice	15	14	12
Hospital Selayang	5	4	4
Gold Coast Hospital and Health Service	13	10	8
St Vincent's Private Hospital Brisbane	4	3	3
Hospice Taranaki	8	3	1
Total	119	98	74

JANE HUNT – RAPID PROJECT OFFICER

Hello everyone

As way of introduction, I have a background in clinical palliative care nursing, clinical trials nursing, clinical trial coordination, project management and since January 2018 project officer for the RAPID Program.

Just a few quick words to say many thanks for all your contributions to data collection and the subcommittees who are developing new series all the time.

Our progress this first half of the year has been fantastic with data collection at a new high and a number of new series launched.

I work 2 days a week - usually Tuesdays and Fridays and I'm always happy to hear from you if you have any comments or problems. I can assist new sites with ethics support as well.

I look forward to a great second half of 2019 with new Series opening up, results papers being published and Amitriptyline reaching 100 data sets.

Don't forget to visit our webpage which shows all the series open for data collection and lots of other useful information regarding all things RAPID.

Kind regards

Jane Hunt RN.

RAPID Project Officer

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https://uts.edu.au/RAPID

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